JUL 2 9 1986

HE 20.3027/2:985-86

COMPLETED

18

1985–86 Annual Report National Arthritis Advisory Board

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
National Institutes of Health

BEST COPY AVAILABLE

1985–86 Annual Report National Arthritis Advisory Board

U.S. DEPARTMENT OF HEALTH
AND HUMAN SERVICES
Public Health Service
National Institutes of Health

NIH Publication No. 86-2043
April 1986

I

BEST COPY AVAILABLE

BLANK PAGE

Contents

National Arthritis Advisory Board iv
I. Introduction 1
II. Recommendations: Funding Priorities 2
III. Positive Steps Toward Arthritis Control 5
IV. Continued Needs: Expanding the Applications of Research to Patient Care 8
V. The Future in Biomedical Research 11
VI. Conclusion 12

BEST COPY AVAILABLE

National Arthritis Advisory Board

Chairman
James R. Klinenberg, M.D.
Los Angeles, California

Wayne H. Akeson, M.D.
San Diego, California

Giles G. Bole, Jr., M.D.
Ann Arbor, Michigan

Maureen Drummy
Washington, D.C.

Jean Goeppinger, Ph.D.
Charlottesville, Virginia

Dawn Hafeli
Dearborn, Michigan

Hugo E. Jasin, M.D.
Dallas, Texas

Matthew H. Liang, M.D., M.P.H.
Boston, Massachusetts

Henry J. Mankin, M.D.
Boston, Massachusetts

Doris S. Melich
Salt Lake City, Utah

Paulding Phelps, M.D.
Portland, Maine

Darwin Prockop, M.D., Ph.D.
Piscataway, New Jersey

Bernhard Singsen, M.D.
Columbia, Missouri

Ralph Snyderman, M.D.
Durham, North Carolina

Allen C. Steere, M.D.
New Haven, Connecticut

Charles Stewart
Little Rock, Arkansas

Fran S. Symms
Alexandria, Virginia

Jane Walter
Hanover, New Hampshire

Ex Officio Members

Arthur J. Lewis, M.D.
Veterans Administration

Samuel Lin, M.D., Ph.D.
Office of the Assistant Secretary for Health, DHHS

Peter Layde, M.D.
Centers for Disease Control

Pierre F. Renault, M.D.
National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases

Thomas E. Malone, Ph.D.
National Institutes of Health

Lawrence E. Shulman, M.D., Ph.D.
National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases

John R. Waterman, M.D.
Department of Defense

Staff

Raymond M. Kuehne

BEST COPY AVAILABLE

I. Introduction

Every year, 1 million Americans learn that they have arthritis, a disease that now afflicts nearly 37 million people in this country. Arthritis costs the Nation an estimated $18.6 billion annually in medical expenditures and associated economic losses. In addition to legitimate medical expenses, Americans spend more than $1 billion annually on quack devices and unproven remedies.

More than 7 million people are disabled by arthritis each year, and an estimated $1 billion is spent annually on disability aid and insurance. Some forms of adult and juvenile arthritis not only cause crippling of limbs but also result in kidney disease, blindness, and premature death. Arthritis is second only to heart disease as a cause of disability payments. For the average patient, arthritis can cost more than $150,000 in lost wages, medical care, and other expenses over a lifetime.

Any measure of economic impact, however, cannot adequately represent the personal and social burden of arthritis. Arthritis is estimated to affect more than 40 percent of the population over the age of 65. An estimated 250,000 children have arthritis or a related joint disease; of these, 100,000 will continue to have serious handicapping conditions into adulthood. Most forms of arthritis are chronic, and many patients require lifelong care.

Arthritis is a term that covers more than 120 kinds of diseases and disorders that occur in adults and children. Included are rheumatoid arthritis, osteoarthritis, all forms of juvenile arthritis, systemic lupus, and many inherited and acquired connective tissue disorders, such as scleroderma. The enormous toll of arthritis prompted Congress to pass the National Arthritis Act in 1975.

The Arthritis Act resulted in the establishment of the National Commission on Arthritis and Related Musculoskeletal Diseases. The Commission developed the Arthritis Plan, which outlined recommendations for research, education, and support services and for the establishment of the National Arthritis Advisory Board (NAAB) to monitor the plan and advise the Federal Government on arthritis-related activities. The Board consists of 18 appointed members who are drawn from the general public and associated medical, surgical, and health disciplines. Additional ex officio members represent Federal agencies with responsibility for related activities.

In reviewing arthritis research and the application of research knowledge to patient care, the Board serves a variety of constituencies: Government officials, scientists, health professionals, educators, patient advocates, and members of the general public.

In the past 9 years, the NAAB has recommended improved program approaches to the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases (NIADDK) and other Federal, State, and private groups based on special studies, program site visits, review of the technical literature, public testimony, and expert advice.

The Board also prepares this annual report for public policymakers to update them on achievements in arthritis research and services and to advise them on current priorities and ongoing needs. The 1985-86 annual report has three objectives:

- To make recommendations for arthritis research funding priorities.
- To review the recent progress made in biomedical research and community education and services.
- To discuss mechanisms for expanding the application of research to patient care.

This year's National Arthritis Advisory Board annual report provides highlights of recent advances in arthritis research and treatment. It includes an analysis of current and recommended appropriations that are needed to achieve the objectives outlined above, which are discussed in detail in the following chapters. The needs and opportunities summarized in this report justify a strengthened and expanded Federal arthritis program.

BEST COPY AVAILABLE

II. Recommendations: Funding Priorities

The National Arthritis Advisory Board is encouraged by the accomplishments of research into the causes and mechanisms of arthritis and the development of new devices, surgical techniques, and drugs that are used to treat arthritis patients. The Board is also encouraged by the increased attention that the private and public sectors are paying to the treatment, education, and information needs of people who suffer from the chronic and debilitating group of diseases termed arthritis. Section III of this report, "Positive Steps Toward Arthritis Control," reviews some of these important advances.

These accomplishments result largely from the impetus generated by the Arthritis Plan that was developed by the National Commission on Arthritis and Related Musculoskeletal Diseases in 1976. The plan identified the major needs and opportunities in arthritis research and treatment and led to a modest increase in Federal appropriations for arthritis-related projects. However, the base of support for scientific investigation has been reduced in recent years because appropriations have not kept pace with the increased cost of biomedical research. Therefore, the research advances we have seen in the past decade are not likely to be duplicated in the future unless additional resources are provided. This reduction in the research base is a major concern to the Board, especially in light of the new and promising opportunities for progress in the prevention, treatment, and early diagnosis of arthritis.

Congress and the administration share the Board's concern about the impact of arthritis on the Nation. In 1985, the Secretary of Health and Human Services identified arthritis research as a departmental priority initiative. The President issued an executive order to establish a separate National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMSD), and Congress authorized the establishment of the new Institute (P.L. 99-158). These actions have laid the foundation for the growth of arthritis-related research programs. However, additional funds must be appropriated before the promise of 1985 can become a reality in 1986 and in the future.

P.L. 99-158 directs the National Institute of Arthritis and Musculoskeletal and Skin Diseases "to expand, intensify, and coordinate the activities of the Institute respecting arthritis and musculoskeletal diseases." This expanded program provides for the following:

- Investigation into the epidemiology, etiology, and prevention of arthritis and musculoskeletal diseases.
- Research into techniques, drugs, and devices used in the diagnosis and treatment of these diseases.
- Research on technological devices that can replace damaged bones, muscles, and joints.

In addition, the Director of NIAMSD is required by the new legislation to:

- Establish a National Arthritis and Musculoskeletal and Skin Diseases Data System.
- Operate a National Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse.
- Provide for new and existing centers for arthritis and musculoskeletal diseases to conduct basic and clinical research; training programs for scientists, physicians, and other health professionals; and information and continuing education programs for health professionals.
- Support projects to develop and demonstrate methods for screening, detection, and referral for the treatment of arthritis and musculoskeletal diseases.
- Establish an interagency coordinating committee for arthritis and musculoskeletal diseases and an interagency coordinating committee for skin diseases.

To implement these important programs, the appropriation for NIAMSD must be increased in fiscal year 1987 and subsequent years. The Board has carefully considered the resources required for the above programs and has provided budget recommendations for fiscal years 1986 and 1987. These recommendations are summarized in table 1 and are described below.

Individual Research Grants: The percentage of approved grants for arthritis and related research projects that could be funded has declined steadily from about 45 percent a few years ago to approximately 25 percent in fiscal year 1985. In fiscal year 1986, this rate will drop even farther under current budget allocations. The Board's recommendations would restore the award rate to approximately 45 percent.

BEST COPY AVAILABLE

Multipurpose Arthritis Centers: As a result of limited appropriations, the budgets of these centers have been reduced administratively in recent years below the funding levels recommended by scientific study sections. In addition, five new centers with excellent priority scores could not be funded within recent appropriation levels. Therefore, the Board recommends the allocation of increased funds for these centers.

Specialized Centers of Research: The Board supports the initiation of multidisciplinary arthritis-related Specialized Centers of Research (SCOR's) that would capitalize on existing geographic aggregates of basic and clinical investigators who are capable of using advanced technology to pursue research on specific diseases. SCOR programs would encourage active collaboration among scientists and disciplines involved in arthritis research issues. The Board's recommendations include funds to establish nine SCOR's by 1987, three each in the areas of rheumatoid arthritis, osteoarthritis, and osteoporosis.

Research and Development Contracts: Contract funds are allocated to selected high-priority projects that require closer direction from Institute staff. The Board's recommended budget includes an additional $500,000 for clinical trials in the area of orthopedics and sports-related disorders in response to P.L. 99-158.

Equipment and Facilities for Extramural Research: P.L. 99-158 directs the Institute to "provide for the development, modernization, and operation of new and existing centers for arthritis and musculoskeletal diseases." Continued progress in research is highly dependent upon the upgrading of outdated facilities throughout the Nation. The Board includes modest funds for this purpose in its budget recommendations.

Intramural Research: Intramural research programs at NIH have continued to lead basic and clinical investigation into mechanisms of disease and the treatment of arthritis and musculoskeletal and skin disorders. This program has been severely hampered by recent reductions in personnel and research resources. The unique capabilities of the NIH Clinical Center must be encouraged and supported at a high level.

Research Career and National Research Service Awards: Previous Board reports have emphasized the increasingly critical problem of an inadequate supply of new investigators who are trained to solve research problems by using modern technology. The budget proposed by the Board includes a modest increase in funds for fellowships, training grants, and research career awards.

Table 1

Budget Recommendations for Fiscal Years 1986 and 1987:
National Institute of Arthritis and Musculoskeletal and Skin Diseases
(Thousands of Dollars)

	1986	1987
Individual Research Grants	$ 99,040	$112,459
Multipurpose Arthritis Centers	15,500	16,275
Specialized Centers of Research	5,000	7,650
Research and Development Contracts	4,160	4,868
Equipment and Facilities for Extramural Research	4,580	4,809
Intramural Research	9,128	9,584
Research Career Awards and Other Research	6,235	7,800
National Research Service Awards	6,250	6,530
Epidemiology and Data Research*	3,380	3,549
Education and Training, Conferences, Seminars, and Workshops	1,050	1,103
Arthritis Information Clearinghouse	229	240
National Institute of Arthritis and Musculoskeletal and Skin Diseases†	—	3,500
Total	**$154,552**	**$178,367**

*Not included in recommendation for research grants.

†A new National Institute of Arthritis and Musculoskeletal and Skin Diseases was authorized by P.L. 99-158. Creation of the Institute is dependent upon the appropriation of funds and personnel for essential administrative and scientific positions. This recommendation includes authorization for 36 new positions.

BEST COPY AVAILABLE

Epidemiology and Data Research: Previous Board reports have emphasized the need for new initiatives in epidemiology and related disciplines. P.L. 99-158 also directs the Institute to establish a "National Arthritis and Musculoskeletal and Skin Diseases Data System for the collection, storage, analysis, retrieval, and dissemination of data derived from patient populations." The Board has included additional funds for this purpose in its recommendations.

Education and Training, Conferences, Seminars, and Workshops: Institute-sponsored conferences and training programs continue to be a valuable tool for technology transfer, information dissemination, and professional and patient education about arthritis and musculoskeletal and skin diseases. These funds support technology transfer efforts such as the NIH Consensus Development Conferences on Osteoporosis and on Total Hip Joint Replacement. They also support workshops on patient education and other research-related conferences such as those discussed in section V of this report, "The Future in Biomedical Research."

Arthritis Information Clearinghouse: The effective dissemination of information about arthritis and musculoskeletal and skin diseases to health professionals, patients, and the public is an essential component of the Arthritis Plan. P.L. 99-158 endorses this activity, and the Board has included additional funds for the clearinghouse in the recommended budget.

National Institute of Arthritis and Musculoskeletal and Skin Diseases: The creation of NIAMSD will require additional personnel and funds for essential administrative and scientific positions. Sponsors of the enabling legislation have documented the need for these additional resources. The positions and funds have not yet been approved. Therefore, the Board recommends that Congress and the administration provide 36 additional positions and $3.5 million to establish the new National Institute of Arthritis and Musculoskeletal and Skin Diseases authorized by P.L. 99-158.

Although NIAMSD is the lead agency for the Arthritis Plan, significant activities are supported by other NIH Institutes, other agencies within DHHS, the Veterans Administration, and the National Institute for Handicapped Research of the Department of Education. Table 2 shows expenditures for arthritis and related diseases by other NIH Institutes. The Board recommends that the administration and Congress provide additional resources to these agencies for arthritis-related activities.

The Board's recommendations represent the minimum resources necessary to continue the overall arthritis program, to establish the new Institute authorized by P.L. 99-158, and to initiate the programs authorized in that legislation. The implementation of these recommendations will move the Nation closer to the goal of reducing the medical, social, and economic impact of arthritis.

Table 2

Expenditures of Other NIH Institutes for Arthritis and Related Diseases
(Thousands of Dollars)

	1983 Actual	1984 Actual	1985 Actual
National Institute of Allergy and Infectious Diseases	$ 8,176	$11,536	$12,845
National Institute of Dental Research	3,087	3,465	3,700
National Institute on Aging	2,058	2,041	1,649
National Heart, Lung, and Blood Institute	1,634	1,728	1,744
National Institute of Child Health and Human Development	1,299	1,552	1,808
National Institute of Neurological and Communicative Disorders and Stroke	1,142	3,206	3,536
National Institute of General Medical Sciences	1,026	1,003	1,230
National Cancer Institute	879	997	811
National Institute of Environmental Health Sciences	72	90	0
Division of Research Resources	3,220	3,551	4,080
Total	**$22,593**	**$29,169**	**$31,403**

BEST COPY AVAILABLE

III. Positive Steps Toward Arthritis Control

Advances in fundamental science are contributing to the knowledge of the disease processes and mechanisms of arthritis, including the role of infectious agents and immunologic and endocrinologic factors. A great deal of progress has been made over the past three decades in understanding these chronic, crippling disorders. Some of these diseases now can be partially controlled with medication and other types of therapy.

The research effort in arthritis encompasses three general areas: projects associated with immune disturbances, autoimmune diseases, rheumatoid factor, antigen-antibody reactions, and immune complex formation; research concerned with the structure and function of connective tissues such as collagen, basement membranes, synovial tissues, and articular cartilage damaged in the rheumatic diseases; and research projects in several specific rheumatic diseases (rheumatoid arthritis, degenerative joint diseases, juvenile arthritis, systemic lupus erythematosus, gout, osteoporosis, and heritable disorders).

A fourth area of basic and clinical research involves the musculoskeletal system in normal and diseased conditions and includes investigations of the properties, growth, and metabolism of normal bone; bone and joint diseases, including metabolic bone diseases and inherited connective tissue diseases; musculoskeletal injury and repair; disorders of skeletal support structures such as tendons and ligaments; and specialized studies in areas such as low back pain and locomotion. The increasingly important areas of exercise pathophysiology and sports medicine are also being studied. Research in joint replacement, bone and cartilage transplantation, and fracture healing has helped to restore mobility and relieve pain for many Americans with orthopedic problems.

This section discusses some of the promising results of nationwide biomedical research activities, biomedical studies at the selected Multipurpose Arthritis Centers (MAC's), and community demonstration programs at the MAC's that test approaches to patient and professional education and service delivery.

Research Highlights

Significant advances in biomedical research, supported by NIADDK and other Institutes at NIH, have improved our understanding of the causative mechanisms of some of the rheumatic diseases. For example, specific agents recently have been found that may initiate or trigger rheumatoid arthritis; these include parvovirus and Epstein-Barr virus. Moreover, only certain persons who are susceptible to rheumatoid arthritis by their genetically determined immune responsiveness develop the chronic and active inflammation of rheumatoid arthritis. Research on newly developed animal models of arthritis is enhancing the scientific knowledge of these diseases. Important information also is being obtained from a human type of arthritis, Lyme arthritis, that was discovered just 10 years ago. It was found recently that Lyme arthritis is caused by a tick-borne spirochete, a bacteria-like organism that can be treated effectively with antibiotics.

Osteoarthritis, the most common form of arthritis, affects 16 million people in the United States. One of the most disabling and crippling diseases in older populations, it has been a difficult disease to study. Two recent research developments point to possible advances in our knowledge of osteoarthritis. In the first, biochemical observations indicate that cartilage cells produce the substances that both build and destroy the cartilage; this may lead to an understanding of why damaged cartilage is unable to repair itself and may help in discovering new ways to induce this repair. In the second development, several new experimental models of osteoarthritis offer the hope for greater knowledge of the cause of and new treatments for this disabling disorder.

Remarkable advances in reconstructive surgery for osteoarthritis and rheumatoid arthritis have been made during the past decade. Improvements have been achieved in total joint replacements for severely damaged hips, knees, shoulders, elbows, and wrists. These results have been achieved through the combined research efforts of bioengineers, rheumatologists, materials scientists, and orthopedic surgeons. Loosening of the joint implant after several years remains a problem. Nonetheless, the future holds a promise for the development of implants that will provide normal joint function over an indefinite period.

BEST COPY AVAILABLE

Systemic lupus erythematosus (SLE) is a serious inflammatory connective tissue disorder that involves many organ systems. SLE is characterized by various immunologic abnormalities, including a large number of autoantibodies (i.e., antibodies that react against a person's normal endogenous cell nuclear constituents). Research on SLE, a condition that primarily affects young women, continues to be active and productive. More is being discovered about abnormal immunoregulation in SLE; a newly identified defect in complement receptors on cells in lupus patients may be inherited. Dietary manipulation can alter SLE in experimental models in inbred mice; nonsaturated fatty acids may inhibit the disease-producing immune reactions in these SLE mice. Hormonal regulation also has been shown to be important in SLE and may explain the predominance of SLE in women.

Scleroderma is another serious connective tissue disorder, predominantly affecting middle-aged women and men but occasionally affecting children. This relatively rare condition is characterized by diffuse fibrosis and vascular abnormalities in the skin, joints, tendons, muscles, and certain internal organs, especially the gastrointestinal tract (esophagus), lung, heart, and kidney. During the course of scleroderma, the synthesis of connective tissue components (collagen and glycosaminoglycans) by cells (fibroblasts) increases, and various humoral and cell-mediated immunologic reactions occur in the vascular system and parenchyma of these organs. It is now clear that very small blood vessels are important in the pathogenesis of scleroderma at a primary level. Studies are needed to link the vascular and immunologic abnormalities with the fibrotic responses in scleroderma. New animal models such as the tight-skin mouse have been developed for such studies. Research also is needed in the biology of cells that line the walls of small blood vessels and the roles of histamines and kinins in these cells.

The research potential is considerable for the spondylitic (spinal arthritis) group of rheumatic diseases, such as ankylosing spondylitis (AS), Reiter's syndrome, psoriatic arthritis, and the gout-associated arthropathies. Ankylosing spondylitis, the prototype of these diseases, is a chronic systemic inflammation that primarily affects the spinal column. Joint involvement in ankylosing spondylitis appears to originate where cartilage and ligaments are attached to bone and the synovium.

Sacroiliac joint involvement is the distinctive feature of the spondylitic diseases, which mainly affect young men and often begin in childhood. An infectious etiology by several different micro-organisms has been reported to be associated with the development of these diseases. The role of the special tissue antigen HLA-B27 in spondylitis needs to be investigated further, as do the reasons that the diseases are predominant among males.

The Board believes that research in the rheumatic diseases is at a critical point for major breakthroughs. New leads are emerging in many areas of investigation. Moreover, the availability of new biomedical research technologies such as monoclonal antibodies, recombinant DNA, molecular genetics, and computers is accelerating the pace of major scientific discoveries.

Biomedical Research Efforts in Multipurpose Arthritis Centers

NIADDK supports 13 Multipurpose Arthritis Centers, which carry out multidisciplinary studies in basic and clinical research, as well as demonstration programs in the educational and health services aspects of arthritis control (discussed in the next subsection). MAC support for biomedical research is designed to encourage young investigators and those new to the field of arthritis to explore interdisciplinary and highly innovative scientific approaches that may later form the basis of applications for traditional research grant awards from NIH or other agencies. Biomedical research is also supported by core units, or common-use facilities, that are designed to increase the effectiveness and efficiency of each center's activities. Core units for tissue culture, connective tissue metabolism, immunology, histocompatibility testing, and hybridoma work are examples.

Biomedical research activities that are conducted at the MAC's include the following:

- Studying the significance of monocytosis in the development of autoimmune disease in BXSB mice.
- Investigating the phenomenon of fibrosis—excess tissue leading to scar formation in organs and joints—in arthritis.
- Studies of arthritic synovial (joint lining) tissue—for example, evaluating the possibility that dendritic cells present in synovial tissue interact with immune T and B cells to influence the pathophysiology of rheumatoid arthritis.
- Employing gait analysis to evaluate the results of total knee replacements to devise a functional performance index that is related to the disability for each lower extremity joint.

BEST COPY AVAILABLE

- Evaluating new imaging techniques to assess early cartilage damage of osteoarthritis.
- Studying the role that viruses may play in murine polymyositis to determine how the immune system affects the disease process.
- Determining if cellular reactivity to cartilage components is correlated with clinical disease in children with juvenile rheumatoid arthritis.
- Investigating synovial-cartilage relationships in experimental osteoarthritis and immune synovitis with respect to prostaglandin metabolism to advance the understanding of relationships among hormones, certain drugs, and inflammation on prostaglandin content and synthesis by synovium and chondrocytes.
- Analyzing the risk factors for osteoarthritis. Radiographs of hands and wrists taken approximately 20 years ago are being reread, and data concerning weight, socioeconomic status, occupational activity, joint symptoms, and biochemical parameters are being analyzed. A computerized data set is being assembled to include interview results, clinical examinations, x rays, and other tests.
- Investigating the relationship of oral contraceptives to the development of rheumatoid arthritis to determine whether the use of oral contraceptives protects women from this disease, as has been suggested. If the protective effect of oral contraceptives is confirmed, it will contribute to our understanding of the pathogenesis of rheumatoid arthritis and will yield information on the relationship between sex steroids and autoimmune disease.

MAC Innovations in Education and Service Delivery

Arthritis is a chronic condition whose alleviation requires exercise, lifestyle changes, and psychological coping skills in addition to medical treatment. Improving the outlook for patients thus involves making strides in educating patients and professionals and in structuring health services to facilitate comprehensive care. The MAC's conduct studies and demonstration programs that promote the application of new knowledge and the results of multidisciplinary clinical research to patient care.

The following highlights illustrate the scope of the MAC's work and their contributions to improving the treatment of arthritis:

- A program at the University of Alabama Arthritis Center in Birmingham has personalized inpatient education about arthritis. A tailored course of instruction replicable in other sites was developed, and patient outcomes were assessed, including pain, anxiety, and functional status. The results revealed that personalized instruction produced significantly more learning in patients than did nonpersonalized education.
- A patient education project at the University of North Carolina Arthritis Center in Chapel Hill is developing ways for health professionals to improve patient compliance with treatment regimens. Each patient is interviewed to identify physical, psychological, social, and environmental inhibitors and facilitators of compliant behavior to help plan effective interventions to increase compliance.
- In a study at the Stanford University Arthritis Center in Palo Alto, California, more than 350 patients have been followed for 7 years with assessments of treatment, disability, symptom levels, patterns of care, and economic impact. Results show that self-reported data from patients are accurate and can be used with confidence by physicians.
- Investigators at the Arthritis Center at Brigham and Women's Hospital in Boston, Massachusetts, are evaluating the effectiveness of lay psychological support provided to children with juvenile rheumatoid arthritis by parents who have been trained in preventing and reducing psychosocial maladjustment in these children and their families.
- Indiana University's Arthritis Center in Indianapolis compared routine arthritis health professional team management in rheumatoid arthritis with occasional referral care by team members. At the conclusion of the study, patients who received standard medical management of their disease demonstrated either no change in their condition or greater disease activity than they had at the onset of the program. Patients who were evaluated regularly by each member of a treatment team (i.e., physical and occupational therapists, social workers, and nurse educators) in addition to their physician had less disease activity, some increases in range of motion, and a tendency to have more positive attitudes about themselves and their families.

BEST COPY AVAILABLE

IV. Continued Needs: Expanding the Applications of Research to Patient Care

Advances in research make it clear that significant and exciting progress is being made in understanding arthritis and in improving its treatment and care. Through mechanisms such as the Multipurpose Arthritis Centers, we are also taking positive steps to translate research advances into demonstrably improved outcomes for arthritis patients. This process is neither simple nor automatic. The multidisciplinary nature of the arthritis community and the factors inherent in the health care system can indirectly affect our ability to give patients the benefits of research progress. The Board has identified five areas where research applications can enhance patient outcomes.

1. Expanding and Standardizing the Collection and Analysis of Epidemiologic Data

Epidemiologic studies of arthritis and musculoskeletal diseases are essential to assess the community's economic and social burden, determine the natural history of the diseases, investigate disease etiologies, and identify risk factors in adults and children.

The National Data Workgroup, which is developing a broader and more reliable data base on the rheumatic diseases, has reported that no descriptive national data sets exist for most rheumatic diseases. For some rheumatic diseases, one or multiple data sources are available but must be used with great care. No single source provides the best national estimates of the rheumatic diseases.

Osteoarthritis, the most frequently reported rheumatic disease, exemplifies the problems with existing data. Osteoarthritis has no uniformly accepted set of diagnostic criteria, and many people with radiographic evidence of osteoarthritis are asymptomatic. Assuming that diagnosis requires x rays, it is unethical and prohibitively expensive to x ray all joints in all persons in a study with adequate sample size. Therefore, the prevalence of radiologic changes that are indicative of osteoarthritis generally must be given for specific joints. Finally, the magnitude of prevalence rates for osteoarthritis varies considerably, depending upon whether only moderate and severe radiologic changes are counted or whether mild changes are also included.

To address these needs, NIADDK, the Arthritis Foundation, and the Centers for Disease Control have collaborated to develop the National Data Workgroup. The workgroup has reviewed disability data and updated current information on the prevalence, incidence, and cost of arthritis. The workgroup soon will publish two journal articles that contain the best available prevalence figures for the major rheumatic diseases and the financial burden incurred by them.

The workgroup has reviewed the data-gathering system of the National Center for Health Statistics (NCHS) and the content of the specific rheumatic disease items included within the surveys conducted by NCHS. The workgroup functions as an advisory body and makes recommendations for future NCHS surveys on arthritis and related musculoskeletal diseases.

Another valuable mechanism for enhancing epidemiologic data resources is the American Rheumatism Association Medical Information System (ARAMIS) that is administered at Stanford University. This multi-institutional data bank gathers prospective information and maintains long-term contact with patients to identify risk factors for arthritis and improve the diagnostic classifications and criteria for rheumatic diseases. A variety of evaluation instruments for epidemiologic studies have been developed within ARAMIS.

NCHS is cooperating with a variety of agencies to develop the third National Health and Nutrition Examination Survey (NHANES-III) instrument to be administered to a national population sample. Questions about arthritis have been included in previous NHANES studies, providing valuable data on morbidity and mortality, on the natural history of rheumatic conditions, and for longitudinal investigation. The Board supports the inclusion of arthritis-related questions in NHANES-III and recommends that NIAMSD allocate the resources necessary to participate.

2. Improving Arthritis-Related Knowledge and Skills Among Health Care Professionals

The Board has identified three skill areas whose enhancement would improve patient care. The first is providing referral information and criteria to primary care physicians. Timely referral to specialized care can make the difference between a poor prognosis and a positive outcome based on state-of-the-art therapy.

BEST COPY AVAILABLE

Second, nurses, physical therapists, occupational therapists, social workers, and other health professionals need more specific training in rheumatology. With up-to-date skills, these providers can have a positive effect on the patient's situation. Similarly, more specific training in rehabilitation rheumatology for primary care physicians would upgrade the support that patients receive from the health care team. This subject has not received adequate attention in educational curriculums.

Third, the ability of health professionals to communicate information to patients about their conditions, treatments, and self-care is an essential skill. Many medical schools and other professional curriculums do not teach practical skills in patient education. Physicians and health professionals need training in behavioral science approaches to patient care and education. Where such programs do exist, they should be accelerated; where they do not exist, they should be instituted.

One resource that aids both arthritis patient management and patient education skills is the Arthritis Information Clearinghouse. The major function of the clearinghouse is to collect, screen, store, and distribute information about educational materials and programs in the rheumatic diseases to health professionals who serve arthritis patients.

The clearinghouse prepares and distributes bibliographies, catalogs, and other materials; helps users locate and select educational materials; refers inquirers to appropriate sources for other information; and provides sample catalogs, bibliographies, and bibliprofiles (brief state-of-the-art reports) for professional meetings. It also offers reference services to educators, clinicians, and researchers in the field of rheumatic diseases. Its data base consists of about 5,000 citations and abstracts of print and audiovisual materials, journal articles, pamphlets, reports, textbooks, and other items. The Board believes that the clearinghouse fulfills a crucial service for health professionals and the patients whom they serve.

3. Improving Patient Education for Persons With Arthritis

Greater knowledge of arthritis is important not only for health care professionals but for patients. Several recent studies offer guidelines for the development of patient education materials. In one study, both health care professionals and patients ranked psychosocial issues first among patient education topics for rheumatoid arthritis; however, health care practitioners involved in diagnosis and treatment often do not address these critical issues. Teaching coping skills to arthritis patients offers one valuable tool in alleviating their psychosocial problems.

Recent studies also show that presurgical patient education reduces postoperative anxiety and pain and expedites recovery, as measured by reduced days to discharge and decreased use of pain medication. The practical application of these findings should include patient education in the preparation for orthopedic surgery.

Juvenile arthritis presents special problems because the family is intimately involved with the treatment and because developmental aspects of the parent-child relationship complicate the situation. Improved patient education techniques for both children and their families are needed.

Finally, members of different cultures have widely varying beliefs and behaviors toward disease that can affect their interactions with the health care system. More research is required about the communications needs of arthritis patients from minority populations. Patient education materials and individual counseling efforts should be targeted to minority needs and characteristics.

4. Improving Access to Arthritis Services by Expanding Third-Party Reimbursement Coverage

Despite the advances made in arthritis treatment, it is clear that certain ethnic and socioeconomic population groups have not benefited as much as others from research progress. Health insurance may be more difficult to obtain for members of these groups, which may interfere with their access to arthritis services.

BEST COPY AVAILABLE

To promote widespread and equal access to the professional and therapeutic services that are required for the optimum care of a chronic disease such as arthritis, financing and reimbursement issues need to be explored for arthritis, as they have been for other chronic diseases, such as diabetes and cancer. In addressing this problem, the following issues need to be considered:

- Availability of health insurance for people with arthritis, including special problems for members of minority groups, low-income populations, and the elderly.
- Coverage for preventive services, including patient education, that could reduce the need for more costly treatment.
- Coverage for therapeutic supplies and devices that have a significant impact on the patient's employability and quality of life.
- Reported problems that are related to prospective payment (diagnostic-related groups) and capitation systems.
- Coverage for the services of nonphysician health professionals, such as physical and occupational therapists and podiatrists.

5. Enhancing the Mechanisms That Facilitate Information Sharing Within the Health Care Community

Activities such as those of the Arthritis Information Clearinghouse, ARAMIS, the Arthritis Foundation, and the American Rheumatism Association provide important mechanisms for disseminating research results and educational information nationwide. Many state and local groups have also developed effective networks for patient and professional education. These efforts have facilitated communication about state-of the-art treatment within the arthritis community. Within the larger health care community, however, gaps still exist between research-based clinical knowledge and the practical application of new diagnostic, treatment, and prevention measures.

The Board is focusing attention on initiatives to address this issue by identifying and ranking opportunities to expand the applications of new research to the primary care physician and other health professionals who are likely to see arthritis patients. The Board will identify rheumatic diseases in which advances in clinical knowledge and management techniques have not been effectively translated into improved patient outcomes at the community level. Based on information from experts within the arthritis community and from other health care professionals, the Board can determine priorities among the areas that need better application to patient care and can develop strategies to accomplish these objectives. The result will be a consensus plan for promoting specific professional and patient practices that can improve the health status of arthritis patients.

BEST COPY AVAILABLE

V. The Future in Biomedical Research

In addition to promoting initiatives that address applying current research results, the National Arthritis Advisory Board is also concerned with the directions that future arthritis research will take. Careful assessment of the current state of the art is a critical first step in planning future research. The recommendations of experts for the most necessary and promising avenues of new investigation are equally essential.

To accomplish both of these steps, the Board is working with other organizations in the development and support of conferences on arthritis topics of interest. These meetings are reviewing completed research and looking at the next steps that the research community should pursue.

Osteoarthritis Conference

A workshop on osteoarthritis, cosponsored by NIADDK, NAAB, the National Institute on Aging, and several voluntary and professional organizations and pharmaceutical firms, was held in July 1985. The conference addressed specific questions about osteoarthritis, such as:

- What are the epidemiologic factors for osteoarthritis?
- What are the roles of acute or chronic trauma in the pathogenesis of osteoarthritis?
- How do the anatomic, physiologic, chemical, and mechanical alterations in cartilage matrix interrelate in the pathogenesis of osteoarthritis?
- What roles do extra cartilagenous structures play in osteoarthritis?
- Does articular cartilage repair itself in trauma and osteoarthritis?
- What are the roles of aging factors in different types of osteoarthritis?
- Under what circumstances does inflammation develop in osteoarthritis?

The outcome of the meeting was a conference-generated report identifying more than 84 areas of study, including:

- The development of new taxonomic systems of osteoarthritis designed specifically for epidemiologic studies.
- The development of suitable animal models and appropriate systems for the study of synovial mediators.
- Studies to elucidate further the alterations observed in calcified cartilage and subchondral bone and the role that these alterations play in the pathogenesis of osteoarthritis.
- Studies of the composition and three-dimensional structure of proteoglycans and the nature of cross-linking of the fibrillar network in the presence of an adhesive protein.
- Prospective studies of the effects of nonsteroid autoinflammatory drugs in osteoarthritis.
- The metabolism of articular cartilage proteoglycans in normal and aged tissue.

The report on this conference will be published.

Research Conference on Bone Destruction in Paget's Disease

NIADDK held a workshop in September 1985 to review current knowledge on the role of the osteoclast in bone diseases such as Paget's disease. Paget's disease is a common disorder of abnormal bone remodeling that causes misshapen and painful bone structures. This workshop was the first to focus on this important topic, which has been the subject of much recent research. Participants discussed several possible etiologies for this condition and generated recommendations for potential treatment of the disease. The results of the conference are being summarized for journal publication.

BEST COPY AVAILABLE

Conference on Rheumatic Diseases of Childhood

The Board and several other arthritis professional organizations cosponsored a conference in March 1986 on the rheumatic diseases of childhood, bringing together basic scientists, health services investigators, educational specialists, and chronic disease experts from adult and pediatric disciplines. This 4-day program was designed to assess and promote new directions in biomedical research related to growth and development, chronic arthritis-related eye disease in children, and the autoimmunity of nuclear proteins. The development of health status measures for pediatric rheumatic diseases was also a focus of the conference.

Arthritis Rehabilitation Research Conference

The Arthritis Interagency Coordinating Committee and the Arthritis Foundation are sponsoring a conference on rheumatology, rehabilitation, and research in cooperation with the National Institute for Handicapped Research to be held in July 1986 at the University of Virginia. The Board is helping to sponsor this conference, which will bring together leading investigators in rehabilitation rheumatology to review the state of the art of research in this field.

Molecular Biology: Its Potential for Advancing Rheumatology Research

During the past 5 years, advances in biotechnology have revolutionized biomedical research. Major advances in many fields of medical research have resulted from the development of monoclonal hybridoma technology, high resolution molecular separation techniques, and in particular, the technology of molecular biology. The Board is planning a conference to determine what impact such advances have had on research related to the rheumatic diseases and what potential breakthroughs might be possible by applying such new techniques to research in rheumatic diseases. The conference will be held on October 19–21, 1986, at the Clinical Center of the National Institutes of Health.

The conference program is designed to bring advances in fundamental molecular research to the attention of young investigators, research associates, fellows in training, and physician scientists. It will facilitate the interaction of experts in gene cloning and molecular and cell biology who have done formative research in areas related to rheumatic diseases. Leading investigators, already using such techniques for the study of rheumatic diseases, will describe their current research and potential applications. In addition, molecular biologists not currently involved in the study of rheumatic diseases will discuss potential applications of such techniques to the rheumatic diseases.

VI. Conclusion

The Arthritis Plan marked an important milestone in the Nation's effort to combat the problems of arthritis. Ten years have now passed since the National Commission on Arthritis and Related Musculoskeletal Diseases issued the plan. These 10 years have witnessed important advances in arthritis research and treatment. Many of these advances are attributable directly to the impetus provided by the Arthritis Plan and have resulted in improved care for people with arthritis.

Over the past 9 years, the Board has assessed the progress of the Arthritis Plan and has reviewed the accomplishments and needs of the Government and the private sector in arthritis. These assessments have formed the basis for recommendations that the Board believes will continue to improve the condition of people who suffer from arthritis. At the same time, the Board has served as an important link between the various members of the arthritis community—patients and their families, health professionals, professional societies, voluntary organizations, academic and research institutions, and Government agencies.

This year marks a new milestone in arthritis research and treatment— the creation of the National Institute of Arthritis and Musculoskeletal and Skin Diseases. This new Institute now joins the 11 other Institutes of NIH as a separate entity, providing a focus for arthritis-related research, training, and education. The Board looks forward to continuing its representation and record of service within the arthritis community in the coming years.

BEST COPY AVAILABLE

DISCRIMINATION PROHIBITED: Under provisions of applicable public laws enacted by Congress since 1964, no person in the United States shall, on the grounds of race, color, national origin, handicap, or age, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity (or, on the basis of sex, with respect to any education program or activity) receiving Federal financial assistance. In addition, Executive Order 11141 prohibits discrimination on the basis of age by contractors and subcontractors in the performance of Federal contracts, and Executive Order 11246 states that no federally funded contractors may discriminate against any employee or applicant for employment because of race, color, religion, sex, or national origin. Therefore, the National Arthritis Advisory Board must be operated in compliance with these laws and Executive Orders.

BEST COPY AVAILABLE